



## Mission Statement

*PONDA is a volunteer network of physicians and psychologists advocating to optimize the well-being of individuals with neurodevelopmental needs in Ontario by promoting evidence informed policy in the systems of care.*

## Newsletter – September 27, 2019

Welcome to PONDA's Fall Newsletter where you can learn what we have been up to in the last couple of months, working to make Ontario a better place for individuals with neurodevelopmental disabilities. With a federal election around the corner (October 21, 2019), this newsletter will suggest topics to bring up with candidates when they ask for your vote, or better yet, when you ask a question at an all candidates meeting!

## What's New

### Autism Diagnosis

PONDA leadership met with Minister Todd Smith, MCCSS, to discuss diagnosis of Autism Spectrum Disorder following the [suggestion](#) by MPP Roman Baber that only developmental paediatricians and psychologists should be able to make such a diagnosis. Upon receipt of a letter written to the minister by PONDA, we were invited to meet and give our thoughts on who should be able to diagnose ASD, and how to balance accessibility to diagnostic services with quality and best practice. To view our ideas on this matter, see our letter to the minister [here](#).

**Bottom line – we feel a variety of physicians and nurse practitioners should be able to diagnose ASD, provided they have the training, demonstrate competency, and have access to subspecialty consultation if needed.** Models of care exist around the province where general paediatricians make appropriate ASD diagnoses, often paired with assessments by allied health practitioners. Mentorship models for general paediatricians and family doctors also exist such as the Autism ECHO project from Holland Bloorview Kids Rehab that builds competency in ASD diagnosis and treatment in community settings.

### Mental Health

Mental health care is stated as a priority for the Ford government, and PONDA is ensuring that individuals with neurodevelopmental disabilities are not forgotten as new policy is developed. Our leadership met with a senior policy advisor at the Ministry of Health to highlight the gaps in access to assessment and treatment for this group. Further meetings are to come, and further discussion on this complex topic will take place at our general membership meeting in November.

## **Leadership changes at PONDA**

Dr. Alvin Loh, developmental paediatrician and medical director at Surrey Place, will be taking over as chair at the November 22 meeting. Dr. Nicky Jones-Stokreef will move in to the Past Chair position, and Dr. Mohammad Zubairi has agreed to become the new Vice Chair. These positions have 2-year terms.

## **Working Groups**

### **Learning Disabilities**

There has been an increased interest by dyslexia advocacy groups to collaborate with PONDA in our promotion of evidence-based intervention for reading disabilities. In particular, ONBIDA has asked to partner with us to request that structured literacy be required by the Education Act of Ontario.

The Advocacy [Toolkit](#) on Literacy Based Learning Disabilities is in its 6<sup>th</sup> edition. A poster promoting the toolkit was shown at the American Academy of Cerebral Palsy in Anaheim, California earlier this month. Professionals need to keep advocating for evidence based instructional practices, particularly for the critical skill of reading. Only by convincing school board by school board of the need for best practices in reading instruction, will our youth at risk for LD have the optimal chance for reading success.

### **Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities (IHCCAN)**

Dr Liz Grier, Family Physician, Dr Yona Lunsky, Psychologist and Dr Alvin Loh, have been meeting to discuss priorities for improving health care capacity. Family medicine residents in all training programs need to be given opportunities to care for adults with neurodevelopmental disabilities. Work has begun to create a funded PGY 3 Family Medicine Intellectual and Developmental Disabilities (IDD) Enhanced Skills program in Toronto, which will add to the only other PGY 3 IDD training program in Ontario, at Queen's University.

The Developmental Disabilities Primary Care Program at Surrey Place, has published [Guidelines for the care of adults with IDD](#), and has updated many tools on their website, [ddprimarycare.surreyplace.ca](http://ddprimarycare.surreyplace.ca), which support the guidelines including some for [Transition Aged Youth with IDD](#). These tools may be helpful for you to use and share with Primary Care Practitioners for patients transitioning to the adult system.

### **New Media**

PONDA podcasts has been a hit ,with 2 podcasts currently available on the topic of Learning Disabilities and highlighting our Advocacy [Toolkit](#) for Literacy Based LD/Dyslexia. Stay tuned for our next podcast coming soon on the National Disability Insurance Scheme in Australia, and what this could look like in Canada.

### **Parent Advisory**

We are pleased to share that we have two parents of children with complex neurodevelopmental disorders who are joining our regular steering committee meetings to help guide our work. We truly appreciate the time they give to PONDA to ensure our advocacy work makes sense to those who matter most, people with neurodevelopmental disorders and their families.

## **News from our partners**

### **AODA Alliance**

This organization, led by David Lepofsky, is an advocacy powerhouse!

The AODA Alliance is looking to strengthen and implement the new Accessible Canada Act. For strategies and skills on how to make this an election issue, please see the link below.

<https://www.aodaalliance.org/whats-new/federal-election-action-kit-raise-disability-accessibility-issues-in-canadas-2019-federal-election/>

Do you have an opinion on accessibility for students with special needs in Ontario schools? For information about the *Framework on accessibility standards in education*, please see the following and send your feedback by October 2<sup>nd</sup> to: [aodafeedback@gmail.com](mailto:aodafeedback@gmail.com)

<https://www.aodaalliance.org/whats-new/send-us-your-feedback-on-our-draft-framework-for-what-the-promised-k-12-education-accessibility-standard-should-include/>

### **Every Canadian Counts Coalition**

Bill Cowie and his team at ECCC is working to promote a National Disability Insurance program in Canada, similar to the NDIS in Australia. PONDA has discussed this idea, and has endorsed the need for further research on this proposal. For more information, see their webpage:

<http://everycanadiancounts.com/our-vision/>

Here are some examples of questions you could ask your local federal candidates about this proposal:

1. As Canada is a signatory to the International Convention of the Rights of Persons with Disabilities, would the Government of Canada under your leadership consider implementing a national publicly funded disability insurance program given that it is the most cost-effective way of meeting its obligations under the Convention?
2. Under your leadership, would the Government of Canada consider appointing a Special Advisor to investigate and make recommendations regarding the operational and jurisdictional challenges associated with implementing a national disability insurance program?

## **Membership**

Membership is open to all physicians and psychologists with an interest in improving the well-being of individuals with neurodevelopmental needs. We advocate for children, youth and adults with a wide variety of neurodevelopmental disabilities. Membership is informal with no fee. We simply add you to our mailing list if you are interested. Feel free to share our newsletter and advocacy tools. ***The more members, the stronger our voice.***

*Please email [pondanetwork@gmail.com](mailto:pondanetwork@gmail.com) if you are interested in joining, especially if you are interested in joining one of our working groups!*

## SAVE THE DATE

The next face to face meeting of PONDA will take place in Toronto coinciding with the [Child Developmental Update](#), a popular CME event with excellent speakers and topics put on by the University of Toronto and Holland Bloorview Kids Rehab. The **PONDA dinner meeting** is an excellent chance to discuss topics important to you and your patients, network with colleagues, and take your advocacy to the next level.

Topics this time will include

1. how to deliver mental health care to people with neurodevelopmental disorders, and
2. how to assess the functional needs of people with NDD in the short and long term in order to determine therapy, funding and other supports.

Location: [Novotel Hotel](#), 45 The Esplanade, Toronto, ON

Date & time: Friday, November 22, 2019, 5:30 – 9:00 PM

Cost: \$65.00 early bird before November 1<sup>st</sup>,  
\$75.00 November 1<sup>st</sup> to November 20<sup>th</sup>,  
\$80.00 at the door.

Contact: [m.s.zubairi@gmail.com](mailto:m.s.zubairi@gmail.com) to register and pay by etransfer, password: Advocacy

## Get Involved

Do you want to learn more about advocacy or get involved in our work? Here are some ideas:

- Join one of our working groups:
  - Improving Health Care Capacity in Adults with Neurodevelopmental Disabilities
  - new communications strategies (podcasts)
  - literacy based learning disabilities
- Attend an OMA workshop to improve your advocacy skills [advocacy@oma.org](mailto:advocacy@oma.org)
- Meet with your local MPP, and voice your opinion on a subject important to you
- Write an Op Ed and submit to your favourite print media
- Send a message to Queen's Park through twitter #onpoli
- Use the Advocacy Toolkit on our website to learn how to approach your local school board and encourage evidence-based intervention for LDs
- Listen to our podcast

Don't forget to follow us on twitter: @pondanetwork and like us on Facebook!

Sincerely,  
Nicky Jones-Stokreef,  
Chair of PONDA

**Steering committee members:** Alvin Loh, Ronit Mesterman, Paige Church, Pam Frid, Jennifer McLean, Mohammad Zubairi, Olaf Kraus de Camargo, Ben Klein, Liz Greer, Jennifer Saltzman-Benaiah